Running Head: The student experience of caregiving

Supporting a friend, housemate or partner with mental health difficulties: The student experience

Nicola C. Byrom

Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, Kings College London

Corresponding author: Nicola Byrom
2.05 Addison House
Guy's Campus
Kings College London

E-mail: Nicola.byrom@kcl.ac.uk

Abstract

When experiencing mental health difficulties, university students turn to their friends for support. This study assessed the consequences of caregiving among a university sample, identifying predictors of caregiving burden among students. 79 students were recruited, through a UK student mental health charity, to complete an online survey. Using the Experience of Caregiving Inventory and the Involvement Evaluation Questionnaire as measures of the consequences of caregiving, students supporting friends, housemates or partners, were found to experience significant consequences of caregiving. Frequency of face-to-face contact and duration of illness predicted more negative consequences of caregiving, but these relationships were not straightforward. The presence and intensity of professional support did not influence the experience of caregiving. The implications of these findings for supporting student carers is discussed.

Key words: Caregivers; Peer support; Youth mental health; Students.

Introduction

The literature on informal caregiving focuses families, and in particular, adults looking after children or elderly parents (1). Less is known about the impact of caring on friends, housemates or partners. Addressing this gap, this study examines the impact of caring within a student sample. Young adults (18 – 24 years) are the least likely age demographic to self-report caring responsibilities, but most likely to experience negative impacts of caring (2). This suggests that student carers may experience substantive negative consequences of caregiving. However, where people are supporting friends rather than family, the research suggests that the consequences of caring will be reduced (3). Thus, the impact that caring is likely to have on students is unclear. Therefore, this study assesses the consequences of caregiving and predictors of caregiving experience among a student sample.

Social support is valuable, providing protection against mental health difficulties and improving wellbeing (4-6). Among students, low levels of social support is a risk factor for poor mental health (7-9). Social support may have this protective effect by enhancing ability to cope (10), reducing stigma around help-seeking (11) and decreasing isolation (12).

However, while providing social support can be a strongly positive experience (13), it is often associated with subjective and objective burdens (14, 15). Caring for someone with mental health difficulties affects daily routines, places stress on interpersonal relationships and is associated with reduced physical and mental health (1, 2, 6, 16-21). Predictors of caregiving burden include duration of illness, time involved in caregiving and contact with mental health professionals, though differences have been observed between studies (1, 22-24).

University students, though rarely recognised as informal caregivers, may take on considerable responsibility for supporting friends and housemates. Students may be more likely to live with friends than family. In the UK only 22% of undergraduate students remain living in their family home during term time (25), indicating that students may be more likely to

live with friends than family, increasing the responsibility they feel for providing support to friends.

The consequence of caregiving on students is of particular relevance as students, by virtue of being young adults, are at high risk of developing mental health difficulties (26-28). Between 1 in 3 (29) and 1 in 5 (30) students are estimated to experience mental health difficulties. One in four students identify that they would turn to friends for help if they felt that they were experiencing mental health difficulties (31) and three in four experiencing mental health difficulties report that they do talk to their friends about their mental health (32). This indicates that substantial numbers of students are likely to be providing some level of support to a friend experiencing mental health difficulties.

This study aimed to describe the consequences and level of caregiving burden for students and identify predictors of caregiving burden, considering frequency of contact, duration of illness and contact with professional support services.

Methods

Participants

Participant demographics are shown in Table 1. Seventy nine students, recruited via social media adverts, completed an online survey. Recruitment was run through the UK charity, Student Minds. As young people are unlikely to identify themselves as caregivers (2), the recruitment adverts and survey referred to students as “supporters,” recruiting students who felt they “supported” someone experiencing mental health difficulties. Student participants are referred to as “students” or “student supporters” while the individuals they were supporting are referred to as “supportees”

Procedure and Materials

The study received ethical approval from Oxford University Central University Research Ethics Committee. After providing informed consent, participants completed an online survey anonymously, completing a set of questions relating to demographics, their relationship with the supportee, the support they provide and the presence of other sources of support. The Experience of Caregiving Inventory (ECI) and the Involvement Evaluation Questionnaire (IEQ), have been identified as suitable scales for measuring the consequences of caregiving (33).

The ECI (35) contains eight negative subscales (difficult behaviours, negative symptoms, stigma, problems with services, effects on family, need for back-up, dependency and loss) and two positive subscales (rewarding personal experiences and good aspects of the relationship). Analysis separates scores for the positive and negative subscales, to give an ECI_p and ECI_n score respectively.

In this study, the "problems with services" and "effects on family" subscales were removed. Consultation with students indicated that they found these subscales irrelevant and difficult to answer. Items from the subscales relating to stigma and the good aspects of the relationship were adapted to fit with the relationship between friends: "feeling unable to have *visitors at home"*, was changed to "feeling unable to *hang out together*" and "s/he makes a valuable contribution to *the household"* was changed to "s/he makes a valuable contribution to *the relationship"*.

The IEQ (European Version; 15) is composed of four subscales: Tension, Supervision, Worry and Urging, relating to encouragement and care that the supporter provides, interpersonal problems in the relationship, and the supporter's worries, coping and subjective burden.

Results

As shown in Table 1, student supporters had relatively high scores on the ECI_n and IEQ, indicating a substantive burden of caregiving. They also had high scores on the ECI_p,

indicating that there were strong positive aspects of the caregiving relationship. Total ECI_n score and IEQ scores were highly correlated, r (68) = .85, p < .001. ECI_p score did not correlate with ECI_n, r (66) = .12, p = .32, or IEQ, r (71) = .04, p = .76.

Primary mental health difficulty and duration of illness (DOI)

Supportees' mental health difficulty and DOI was identified indirectly via reports from the supporting student. The relationship between DOI and consequences of caregiving was assessed separately for students supporting someone experiencing anxiety, depression or a combination of the two (n = 40), where a longer DOI predicted higher ECI_n scores, R^2 = .13, B = 6.89 (3.05), 95% CI (.71, 13.08), β = .36, *t* (35) = 2.26, *p* = .030, and students supporting individuals with other mental health difficulties (psychosis, eating disorders, bipolar disorder, OCD; n = 39), where DOI did not predict ECI_n, R^2 < .001, *t* (29) < 1, *p* = .93.

Relationship and frequency of contact

As shown in Table 1, student supporters saw the supportee (face-to-face) several times a week, but were in contact via phone, text, and social media (non-face-to-face) every day. The frequency of contact, ECI_n and IEQ score varied with the relationship, as shown in Table 1; partners had higher scores than friends on the ECI_n, *t* (20.05) = 2.57, *p* = .018 and IEQ, *t* (27.22) = 2.39, *p* = .024.

Further, frequency of face-to-face contact predicted higher ECI_n, R2 = .06, B = 3.74 (1.77), 95% CI (.20, 7.28), t (65) = 2.11, p = .039, and IEQ scores, R2 = .09, B = 2.85 (1.04), 95% CI (.78, 4.92), t (73) = 2.74, p = .008. As shown in Table 2, frequency of contact continued to predict IEQ score after considering relationship. While the relationships with frequency of non-face-to-face contact were in the same direction, these did not reach significance.

Other sources of support

Most supportees were receiving support from two or more professionals, including health care (e.g., GP, nurse) or mental health (e.g., psychologist, therapist, psychiatrist) professionals and university support services (e.g., university counsellor, mental health advisor). However, approximately 15% of supportees were not receiving any professional support. Intensity of support was calculated as the sum of frequency of support from different sources of support, where frequency is given as: 1 = less than monthly contact; 2 = monthly contact; 3 = weekly contact; 4 = more frequent contact than weekly. The intensity of non-professional support (family and friends; X = 5.13, SE = .38) was significantly higher than intensity of professional support (X = 3.28, SE = .29), t (78) = 4.37, p < .001.

Whether or not the supportee had professional support did not predict ECI_n, t (66) < 1, p = .99, ECI_p, t (71) < 1, p = .83 or IEQ scores, t (73) < 1, p = .71. Neither the intensity of professional support, *t* (66) < 1, *p* = .93, non-professional support, *t* (66) < 1, *p* = .58, or the combined intensity of professional and non-professional support, *F* (2, 65) < 1, *p* = .84, predicted ECI_n score. Similarly the combined intensity of support did not predict IEQ score, *F* (2, 72) < 1, *p* = .83.

Intensity of support may have an indirect effect on the experience of caregiving, as shown in Figure 1. Supporters rated the relative level of support that they provided, compared to all other support, on a scale of 1 to 10, and most (median) supporters estimated that they provide 40% of all support. The self-estimated proportion of support provided by the supporter mediated a relationship between the intensity of non-professional support (friends and family) and (1) ECI_n and (2) IEQ. Mediation analysis is summarised in Table 3. As the intensity of non-professional support increases, ECI_n and IEQ scores decrease, mediated by reduced proportion of support provided by the supporter. It is important however to note, that while there is an effect of mediation, the mediated pathway still falls short of predicting a significant proportion of variance in ECI_n score, R^2 = .08, F (2, 65) = 2.85, *p* = .065 or IEQ score, R^2 = .08, F (2, 72) = 2.97, *p* = .057.

Predicting ECI and IEQ scores

Combined, DOI, frequency of contact and self-estimated proportion of support provided predicted ECI_n and IEQ scores, as summarised in Table 4. DOI and frequency of contact explained a significant proportion of the variance in ECI_n score. Only frequency of contact explained a significant proportion of the variance in IEQ scores.

Qualitative analysis of the experience of caregiving

To further understand the factors that influence a student's experience of caregiving, student supporters were asked "Do you think that the mental health difficulties faced by the person you are supporting have had an impact on your quality of life?" 61 supporters (77%) answered this question. Responses were categorised as indicating that the supportee's mental health had no impact (6%), a mix of positives and negatives (9%), a positive impact (10%), minimal negative impact (14%) and substantive negative impact (38%). Of those identifying challenges, some described providing support as stressful (11%) or emotionally draining (6%). Some supporters felt that providing support required them to make compromises with their own lives (14%) and felt responsible for the person they were supporting (13%).

> "I worry about leaving them alone and I often opt out of nights out or family events to make sure they aren't alone for too long."
>
> "When I was trying to support her it put a huge strain on my confidence and mental health as I felt responsible for her, if I wasn't around to help her and something went wrong it was my fault."
>
> "I get anxious every time I get a message from them, which is most days. I just know it is going to be something negative again. It feels like a big responsibility and I always worry about saying or doing the wrong thing. It is also a continual worry that they might hurt themselves."

A few students identified that they had put boundaries in place to limit their responsibility and look after their own mental health (5%).

> "I had to learn to draw a boundary and realize that there is not much I can do to help them. I do what I can, the way I would hope someone would do for me... but I also focus on my own happiness."

Discussion

The consequences of caregiving for students, as measured by the Experience of Caregiving Inventory (35) and Involvement Evaluation Questionnaire (15) is substantive. As a benchmark it is of interest to note that ECI and IEQ scores for student supporters were comparable to data from other research with familial carers (15, 24). Both the prevalence of mental health difficulties among the student population (29, 30) and the proportion of students experiencing mental health difficulties who turn to friends for support (32) suggest that many students are taking on responsibility for supporting a friend through mental health difficulties and data reported here indicates that the impact of this responsibility is not insubstantial.

Similar to existing literature on the caregiving (1, 22, 23), more frequent face-to-face contact and longer duration of illness predicted more a negative consequences of caregiving. However, these relationships are not straightforward. Duration of illness did not predict consequences of caregiving for students supporting someone with a more complex mental health difficulties (eating disorders, OCD, psychosis and bipolar disorder, were analysed as a group). Further, frequency of face-to-face contact was not independent of the type of relationship; partners and housemates have more frequent contact than friends. Controlling for relationship, frequency of face to face contact continued to predict some consequences of caregiving. This analysis highlighted that partners are at particular risk of negative consequences of caregiving, suggesting that particular attention should be paid to students supporting a partner through mental health difficulties.

Research with familial carers has indicated that contact with mental health professionals improves the experience of caregiving (1, 22, 23). Interestingly this finding was not replicated in this student sample; experience of caregiving for students did not improve with more contact with mental health professionals. It is possible that this reflects other changes that co-occur with the intensity of professional support. For instance, as the severity of a student's illness increases, the intensity of professional support may increase and experience of caregiving may become more negative. This survey did not have an independent measure of illness severity, thus we cannot rule out the possibility that this accounts for the lack of relationship between professional support and experience of caregiving.

While this finding requires replication, it raises an important issue regarding the lack of acknowledgement of friends by professionals working with young people with mental illness. Students reported a lack of connection with the professionals providing support; in this survey 55% of students reported wanting to have contact with the professionals providing support but only 4 students reported having any contact with these professionals. Professional service providers do not commonly engage with a client's friends, but this may be highly relevant for youth mental health.

This is not to say that wider sources of support for the supportee are not important. The analysis suggests that the proportion of support provided by the student supporter may be reduced by increasing the intensity of other non-professional support and this in turn may improve experience of caregiving. This highlights the importance of non-professional support, including friends and family.

Clinicians and researchers have recognised that, while family play an important role in caring for an individual experiencing mental health difficulties the consequences of caregiving for familial carers can reduce their ability to provide effective care (34). Skills based interventions for familial caregivers have shown promise (36-39). The findings of this study

should encourage us to ask the same questions about younger carers; students supporting friends may be able to provide more effective support if they are supported as caregivers.

This is a small scale preliminary study, with several limitations. Importantly, the nature and severity of the supportee's mental health difficulty was determined by reports from the supporter. Future work needs to consider the caregiving relationship from the supportee's perspective as well.

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Table 1. Participant demographics.

	Total (*n* = *79*)	Friend (*n* = 43)	Partner (*n* = 20)	Housemate (*n* = 15)	Statistics
Age (SD)	21.77 (3.47)	21.88 (4.03)	21.65 (2.85)	21.47 (2.62)	χ^2 (2) = .05
Length of relationship (SD)	4.82 (1.29)	5.07 (1.37)	4.45 (1.23)	4.47 (0.83)	χ^2 (2) = 5.86
Gender; Female	62 (79%)	36 (84%)	12 (60%)	13 (87%)	χ^2 (2) = 5.85
Currently Co-habiting	53 (67%)	4 (9%)	8 (40%)	14 (93%)	χ^2 (2) = 35.41***
Supporters: experiencing mental health difficulties					
Current	37 (47%)	20 (46%)	9 (45%)	8 (53%)	χ^2 (2) = .27
Previous	20 (25%)	12 (28%)	5 (25%)	2 (13%	χ^2 (2) = .37
Consequences of Caregiving					
ECI_n (SD)	70.78 (2.91)	63.49 (2.42)	85.28 (8.14)	71.46 (5.55)	*F* (2, 65) = 5.70**
ECI_p (SD)	38.95 (1.28)	37.10 (1.65)	40.28 (2.67)	42.27 (3.13)	*F* (2, 69) = 1.37
IEQ (SD)	50.48 (1.79)	46.90 (2.13)	58.39 (4.30)	50.07 (3.59)	*F* (2, 71) = 3.73*
Frequency of Contact					
Face-to-Face	Several times a week	Every few weeks	Daily	Daily	χ^2 (2) = 25.10***
Non-face-to-face	Daily	Several times a week	Daily	Several times a week	χ^2 (2) = 9.54**

Demographics refer to the survey respondent, the student supporter, reflecting their own age, gender, mental health, ECI_n, ECI_p and IEQ score. Statistical significance is marked as: * p < .05; ** p < .01, *** p < .001

Table 2. Relationship type (predictor 1) and frequency of contact (predictor 2) predict scores on the ECI_n and IEQ.

	Face to face	Non-Face to face
Predicting ECI_n		
Combined Model	R^2 = .07, F (2, 65) = 2.54, p = .087	* R^2 = .09, F (2, 65) = 3.39, p = .040
Relationship	B = 3.56 (4.38), t (65) < 1, p = .42	B = 6.27 (3.61), t (65) = 1.74, p = .087
Frequency of contact	B = 2.77 (2.14), t (65) = 1.30, p = .199	B = 5.49 (3.02), t (65) = 1.82, p = .074
Predicting IEQ		
Combined Model	* R^2 = .09, F (2, 71) = 3.70, p = .030	R^2 = .06, F (2, 71) = 2.42, p = .096
Relationship	B = .09 (2.33), t (72) < 1, p = .97	B = 2.20 (2.13), t (72) = 1.03, p = .31
Frequency of contact	* B = 2.83 (1.20), 95% CI (.49, 5.16), β = .30, t (72) = 2.41, p = .018	B = 3.19 (1.75), t (72) = 1.82, p = .073

Significance levels marked, * p < .05, ** p < .01.

Table 3. Mediated relationship between intensity of non-professional support and (1) ECI_n, and (2) IEQ, as shown in Figure 1.

Analysis 1, where Y = ECI_n; n = 68							
Direct Path	β	LCL	UCL	Indirect path	β	LCL	UCL
a_1	**-.38**	**-.54**	**-.22**	**a_1b_1**	**-1.12**	**-2.41**	**-.20**
b_1	**2.93**	**.40**	**5.47**				
c'	.65	-1.27	2.56				
Analysis 2, where Y = IEQ; n = 75							
Direct Path	β	LCL	UCL	Indirect path	β	LCL	UCL
a_1	**-.39**	**-.55**	**-.24**	**a_1b_1**	**-.75**	**-1.49**	**-.20**
b_1	**1.91**	**.35**	**3.48**				
c'	.68	-.53	1.88				

Confidence limits (LCL = lower confidence limit; UCL = upper confidence limit) refer to bias corrected bootstrap 95% confidence limits.

Table 4. Frequency of contact, duration of illness and self-estimated proportion of support provided by the supporter to predict scores on the ECI_n and IEQ.

Predicting ECI_n	
Combined Model **	R^2 = .19, F (3, 64) = 5.03, p = .003
Frequency of Contact *	B = 3.74 (1.69), 95% CI (.36, 7.13), β = -.25, t (64) = 2.21, p = .031
Duration of illness *	B = 5.00 (2.17), 95% CI (.66, 9.34), β = -.26, t (64) = 2.30, p = .024
Proportion of support provided	B = 2.01 (1.05), t (64) = 1.92, p = .059
Predicting IEQ	
Combined Model **	R^2 = .17, F (3, 71) = 4.71, p = .005
Frequency of Contact *	B = 2.74 (1.04), 95% CI (.66, 4.81), β = -.29, t (71) = 2.63, p = .010
Duration of illness	B = 2.46 (1.38), t (71) = 1.78, p = .079
Proportion of support provided	B = 1.05 (.66), t (71) = 1.58, p = .118

Significance levels marked, * p < .05, ** p < .01.

Figure 1. Hypotheses for the relationships between intensity of non-professional support, estimated proportion of support provided by the supporter and ECI_n / IEQ using mediation analyses. Showing, c', direct effect of X on Y and a1b1, indirect effect X on Y mediated by M.